CALIFORNIA MENTAL HEALTH
STIGMA & DISCRIMINATION REDUCTION ADVISORY COMMITTEE

December 17, 2008 Meeting Summary

1. Welcome and Agenda Review

Barbara Marquez, Chief of Prevention and Early Intervention for the California Department of Mental Health (DMH), welcomed people to the third meeting of the California Mental Health Stigma and Discrimination Reduction Advisory Committee (AC for short), held at the Sacramento State Alumni Center in Sacramento.

Julia Lee, Facilitator from the Center for Collaborative Policy (CCP), Sacramento State, reviewed the meeting objectives and walked AC members through the day's agenda, which was focused on identifying strategic directions for the plan. All the day's materials are posted online on the AC's website, http://www.dmh.ca.gov/PEIStatewideProjects/AdvisoryCommittee.asp

2. Overview of Plan Outline

Kirsten Deichert, Information Officer for Communications and External Affairs, DMH, welcomed AC members and reviewed the outline for the strategic plan, using the Suicide Prevention Plan as an example for comparison. The outline had four parts: (1) The Problem and the Challenge, (2) Strategies for Reducing Stigma and Discrimination, (3) Recommended Actions, organized by Strategic Direction, and (4) Next Steps. Kirsten explained that her presentation and the day's work would focus on the second part of the outline around identifying strategic directions for California.

3. Moving from Problems to Strategies

Kirsten presented different models for understanding stigma and discrimination reduction efforts to the AC. Approaches included biomedical, health promotion, rights, social inclusion, and recovery. Kirsten reiterated that each model has strengths and weaknesses, and no single model has a monopoly on effectiveness. Indeed, many approaches are similar and overlap. The second part of Kirsten's presentation focused on the broad strategies that are being tried around the

world. To help organize this information, Kirsten focused on (1) target populations – who?, (2) levels of intervention – where?, and (3) process approaches – how?.

Questions, Comments, and Discussion

1. *Question: Have there been direct education strategies or protest strategies aimed at specific myths associated with mental illness, like dangerousness?*
    a. Reply: The easiest strategies deal with visibility – public service announcements and posters. Then there are personal contact stories. But nothing specific comes to mind with regard to tackling dangerousness.
    b. Comment (from another AC member): The work of Otto Wahl and the MacArthur Risk Assessment Study both address stereotypes of violence, including media messages. The Cinemania stigma website is also notable.
2. *Comment: It would be helpful to add a short explanation of the overall message for each approach.*
    a. Reply: This is implicit in the list of common traits.
3. *Comment: Another myth is that people do not recover, yet good long-term research by Courtney Harding shows that many people do recover.*
4. *Question: Does data exist on specifically what types of contact are most effective, how long it needs to be, what age groups should be paired, what people should be involved?*
    a. Reply: A second research synopsis designed for the AC will cover this.
5. *Comment: The mental health system must be examined – ideas about chronic illness and no hope are disputed by recovery models. A 2000 report by the National Council on Disability found that the mental health system is discriminatory and removes clients from decision-making and subjects them to unwanted treatment. Most campaigns ignore the stigma within the mental health system, the exception being the On Our Own plan from Maryland. This kind of sane-ism and mental-ism is comparable to racism and sexism, and hurts people.*
    a. Reply: This afternoon we'll be focusing on systems as partners.
6. *Comment: A white elephant in the room that nobody seems to want to admit is that sometimes people with mental health issues do fall into violence. Mental health profiling exists on the streets. So a big issue we face is that the lay person has no concept of what mental illness is.*
7. *Comment: While honoring that last comment, speaking from personal experience the side-effects of medication sometimes play a part in that. From the perspective of a consumer, it's just as scary to be on the other side and be confused and not know what's going on with your body, and then when you go out in public to see the reactions others have to you – you react accordingly to the fear you have yourself. So when we work on strategies we have to keep in mind that the other person may also be afraid and scared, and the issue of medication side-effects needs to be integrated in whatever approaches the AC puts forward so that people recognize this factor.*
    a. Reply: We will note this.
8. *Comment: People act bizarre when they have mental illnesses, and we're here to let paramedics and police and fire departments know that certain parts of mental illness are like this, it's just different behavior. Money needs to go into training people to have a calm, tolerant response.*

9. *Comment: The Rockefeller Foundation found that a major weakness with media campaigns is that they bring experts in who tell the community how to do things. The communities we're trying to work with need to help design campaigns so they say what their issues are and how they should be resolved.*
    a. Reply: Yes, and campaigns can include efforts that extend beyond just the media, for example, grassroots campaigns that involve talking with people.
10. *Comment: In our community the RAP program helps people with mental illness become more aware of when they feel good or bad and what their triggers are, and helps communities discussion this behavior, embrace it, and respond appropriately. It goes to the crux of recovery programs – nothing about us without us.*
11. *Comment: It seems like a key element of our strategies should be showing successful people or the average incidence of violence – without tackling the fear of violence we will not get very far.*
12. *Comment: Education is not one of these approaches.*
    a. Reply: Education is part of all of these – it's a big "how."
13. *Comment: We must avoid jumping to conclusions – drinking alcohol does not always equate with having mental health issues.*
14. *Comment and Question: People without mental illness are just as violent as those with mental illness, and a big part of the problem is communication. Are there examples of where models work together – for example, linking the biological model with the health model, showing treatment and creating healthier environments and helping people come out?*
    a. Reply: Approaches are blended and there are many examples where different perspectives are brought together, and evaluation is a critical piece of what we're doing. The next research synopsis will cover examples where people come out.
15. *Comment: Another elephant in the room is that the Mental Health Services Act (MHSA) stakeholder process has disempowered consumers and been very divisive because consumers do not have the negotiation and political skills to come to the table. So in my county the consumer movement has practically no stakeholders involved. The consumer movement must be near the center of our work.*
    a. Reply: All examples presented have concluded that consumers and family members need to be involved at every level of decision-making. In this process we want to ensure all perspectives are honored, and asked third-party facilitators to help ensure this.
16. *Comment: Another elephant in the room is that we're all living under a mainstream belief system which is sometimes the foundation of what gets stigmatized. A person's behavior must be evaluated in the context of their cultural interaction with mainstream culture, which may not accept their cultural behaviors.*
17. *Comment: The models are helpful but hard to distinguish. Regarding campaigns, there is a great website called Half of Us, geared toward college students and mental illness.*
18. *Comment: In the primary care environment we use a bio-psycho-social model that ties all components and pulls all resources together.*
19. *Comment: Messages cannot be effective if people are in denial. The Latino Leadership Council did a community readiness assessment, which told us at what stage on the continuum our population is. They are in denial, which means our message will not be focused on social marketing (behavior change) but education. Otherwise, they will not*

listen. In our county, they asked us the Latino perspective, but they held meetings during the day, when people were working an unable to come. So, we pushed back their timeline and said that if they continue to hold the meetings during the day, they need to give us more time to hold additional meetings to gather meaningful input from our people.

20. *Comment: Other personal issues like the use of condoms or erectile dysfunction have become mainstream in Latina Latino communities and other places. We need to think outside of the box and learn from these campaigns and how they guide people to talk more openly about these things.*

21. *Comment: The MacArthur Community Violence Risk Study concluded that people diagnosed with serious mental illness are no more likely to be violent than other community members. There needs to be more training around crisis intervention and consumer perspectives and medication side-effects. This includes informed consent by consumers who can make educated choices. On the models, there are other medical issues not covered by those. Not all underserved communities support the mental health model, and the issue of screening can be controversial among Latinos because of misdiagnosis and a history of forced treatment.*

22. *Comment: Behaviors can be normal but labeled abnormal and this is something we have to watch for – why are certain groups relegated to negative stereotypes? Often it's not what someone's actions are but just the fact that they're labeled. I find it offensive to say "the mentally ill." We have to see people in their totality.*

23. *Comment: There is information on both sides of the mental health and violence issue. Also, we may want to ask Glenn Close, a celebrity who has talked recently about family members with mental illness, to join California's campaign.*

24. *Comment: In our strategies we need to consider full integration. Downtown Oakland is being gentrified and I'm concerned about efforts to get mentally ill people off the streets. Full integration means that when you walk down the street or at work or at home or at the doctor's office you're not stigmatized, you are accepted across the board, and if you do display symptoms that aren't socially acceptable you do not feel like you have to change. We all are different, I want to be able to talk to myself and not have somebody lock me up.*

25. *Comment: Three months ago I was scared I was having a heart attack. I went to the hospital and was apprehended by the police and paramedics and held in seclusion for eight hours. Why did that happen, why was I so threatening? I'm white and well-educated and have no history of violence, I was just scared and not seeing things correctly – so why wasn't I treated? It's the culture, the system. This needs to stop.*

4. Identification and Discussion of Plan's Strategic Directions

Susan Sherry, Center for Collaborative Policy, guided the AC into the next exercise. Susan explained that staff had sorted AC information and made a list of people who are stigmatized (who) and contexts in which this occurs (where). A conscious decision was made to focus on systems and organizations as partners. Susan walked AC members through a list of four draft strategic directions generated by staff, and explained that the rest of the day would focus on refining these while keeping the "who" and "where" components in mind. Julia Lee noted that people were assigned to sit at tables with diverse stakeholders to encourage people to think about the issues in totality.

After an hour of facilitated discussions everyone did a gallery walk – they walked around the room and examined the list of proposed strategic directions that each small group had generated, written on flip-chart paper, and posted on the walls. A complete list of these directions is found in Appendix A.

Susan then summarized the work of the groups. She noted that three of the tables kept the four trial balloon directions with minor modifications. In addition, she highlighted several themes that emerged from the groups, including:

(1) Transforming attitudes and beliefs
(2) Addressing discriminatory actions and holding people accountable for achieving equality
(3) Gaining and applying knowledge
(4) Creating opportunities in cultural communities (multiple stigmas)
(5) Education, training and awareness on a global level, including the public and society and institutions and systems
(6) Eliminating barriers to full participation in society
(7) A culture of inclusion and collaboration
(8) Changing organizations and systems and their policies and practices
(9) Developing a statewide system for coordinating resources, policies, and practices, e.g., coordination in hotlines
(10) Consumer, family, and community participation in the design and implementation and research on stigma and discrimination programs

Susan encouraged AC members to comment on this list and provide direction to staff on the strategic directions, particularly on themes that might be combined and how this might be done.

Comments and Discussion
1. *Comment: The statewide coordination could be more of a consortium or clearinghouse with responsibility for all the actions associated with transforming attitudes and beliefs.*
2. *Comment: There are many different cultures, but Latino and Native American and African-American are special because people are discriminated against based on the color of their skin, while gays and lesbians are not discriminated against immediately unless they disclose. So ethnic cultures should be highlighted.*
3. *Comment: Language is critical. We carefully crafted our four strategic directions. The word "institutions" has negative overtones, and creating "opportunities" sounds paternalistic. We want legal equality with everyone else in the country the ability to live our lives and have the choices that everyone else has.*
4. *Comment: "Institutions" sounds clinical and very formal, yet other organizations also have protocols, for example gangs.*
5. *Comment: I see five themes: (1) accountability in terms of public policy and legal rights, whether enforcing or creating new laws; (2) research and evaluation of effective methods – maybe suitable for the clearinghouse; (3) transforming attitudes and beliefs, public awareness, and global education; (4) full participation for equality, elimination of barriers, full inclusion in design and implementation, cultural awareness, etc; and (5)*

changing organizational biases and practices, training that includes first responders, DMH, hospitals, police, and providers.

6. *Comment: Creating opportunities in cultural communities should not just be limited to communities of color – transgender and other people get targeted.*

7. *Comment: Two things are missing: (1) self-stigma or shame associated with being a family member or recipient of services – this needs to be kept separate because of barriers associated with community integration and access to services; (2) the need to address discrimination as a distinct focal area separate from generalized approaches to stigma. Also, it needs to be clarified that consumers and families participate in the design of stigma and discrimination reduction programs.*

8. *Comment: Culture should include schools. Schools are a culture just like ethnic cultures. It's a context and a culture. We need to develop strategic interventions that target the whole context. The public health model needs to be linked to changing organizations and systems and policies, and schools should not be lost here.*

9. *Comment: Another thing missing is social support in the community. Even if we assume we'll be able to change people's minds this will take time and we need to ensure support services are available for consumers and non-consumers to make the transition easier. This will fall under many categories and areas including education.*

10. *Comment: The power differential between consumers and DMH in stakeholder processes must also be addressed. People feel hurt and disappointed and disenfranchised. Full participate in design and implementation is not being achieved.*

11. *Comment: The mental health system still has double-standards around inclusion, there's a lot of rhetoric and little reality. Mental health clients are pre-judged as not being able to recover. Enforcement of standards is needed.*

12. *Comment: This process should start with clients and permeate the whole system. Clients should establish the priorities, define what stigma is, and what should be done. They have to get to the top so mental health professionals and DMH are not prescribing the pill that will heal you. They need a major role in the process and I do not see that happening.*

    a. *Reply by Susan: That is another element in the room and it's important to bring this to the group's attention. I think people believe that things start with the consumer, but at the same time that we must honor all perspectives. It is not either-or, it is both-and. We must honor all perspectives while starting with the consumers.*

13. *Comment: Along with social support and services we need to include technical support – advice and protocols for starting programs. Second, contact and exposure are missing.*

14. *Comment: With regard to public policy, funding sources and elected officials must be included.*

15. *Comment: Also with regard to public policy, both the individual and the family must be highlighted.*

16. *Comment: Clients need to be at the top of the list, and cultural brokers for youth and children – themselves if possible. On schools, I oppose saying this is a culture. Schools have a culture but are not an oppressed culture in society, rather they are a place where oppression takes place. Organizational culture is something to look at, but let's be clear.*

a. *Reply by Susan: Let me remind people that this is a consensus-seeking process, and I will do everything I can to find common ground. If divisions persist we will send up multiple things to DMH.*

17. *Comment: We're creating a statewide plan to share with DMH and the Governor. It is for the whole state! I get disturbed when we talk about whether someone is or is not a consumer because I do not see this as an us-or-them issue. Many people across the State are affected by mental health issues, whether their own or those of family members. I go in a lot of boxes, and get worried when say assume that people do not have any experience with stigma just because they haven't been chosen to represent a consumer group.*

18. *Comment: I see both sides. I wear four -isms – I am female and black and sometimes the youngest person in the room and a consumer. When I walk in I do not expect anyone to understand what I'm going through. So when we talk about transformation and inclusion I can't tell you to think a certain way. Just respect me. I do not want to feel I have to lay out these labels and whether you're in this community or that culture. It's so much more about saying how you want to be treated no matter who you are or what institutions are involved. We're looking for equal rights, policies that protect us, and access. The main thing is just respect so on an individual basis any person in the community is treated like you would like to be treated. On the systems level that's a whole other level, but on the basis of who wants to be included in terms of culture and ethnicity, it's about respect.*

19. *Comment: Schools can be both a culture and a context. It's a primary place where Native American children are at risk of developing self-stigma.*

20. *Comment: There's oppression in schools. My small organization dealt with a suicide yesterday. Typically a significant factor is whether a child was excluded and isolated.*

21. *Comment: I do not see the us-them discussion as valuable, but I do think that people who demonstrate their life experience in a public way and represent a community of people do bring something different to efforts to do the contact and change society.*

a. *Reply by Susan: Another tension is that while organized consumers represent one perspective other consumers need a voice too. This is something people came and expressed privately to me, and felt uncomfortable talking about, so I am sharing it. We can address both here, but need to be aware that when we say consumer-driven this includes many consumers who are not organized.*

22. *Comment: The older adult community can also be talked about as a culture unto itself.*

23. *Comment: Regarding consumers who do not have a voice, we need to create job opportunities for them so they can advocate and talk about their lived experiences and be valued and included and considered professionals. That's why we're advocating, we're here to make that true, that's one of our goals.*

24. *Comment: Is the more accepted term "seniors" or "older adults"?*

Susan encouraged anybody who had comments that could not be shared in the moment to provide these to the notetaker, Dorian Fougères from CCP, for inclusion in the meeting minutes.

5. Wrap Up, Homework, Meeting Evaluation

Susan noted that another survey would be sent to the AC regarding how members might help with the public workshops. Members requested the option to save entries in progress, to see

questions at the start, and to have more time to submit responses. Susan clarified that only members should actually fill out the surveys. Members are welcome to consult their constituents before filling out the surveys, but should let staff know if they do this so they understand the context of the information. It is also helpful if members can summarize what their constituents say, rather than enter everything verbatim.

Nancy Kincaid, Chief of Communication and External Affairs for the California Department of Mental Health (DMH), explained that this was challenging because the timing of the process. Earlier the Governor's executive order to stop work delayed things, and now the urgency is coming from the lack of a state budget. The concern has been that the process will not be completed in a timely fashion. Nancy explained that she understands the pressure this puts on AC members, and asked them to bear with us, and explained that she would try to extend the calendar if possible, but that everyone was under the pressure of the Legislature.

Julia Lee then led the AC in evaluating the meeting.

PLUS	CHANGE
+ Conversations in small groups	Δ Need to challenge the comment that organized consumers are only talking on their own behalf and a silent majority of consumers are not being represented – this conveys that the consumer movement is not a legitimate representative and spreads discrimination
+ Bringing up alternative viewpoints in a non-threatening way, even disagreements	
+ Bringing up alternative viewpoints in not just a respectful but a very sincere and sensitive way, rather than a provocative and challenging way	
+ Bringing undercurrents and tensions into the room in a transparent way	
+ Leading members through a process that will develop into a beautiful product	

Eduardo Vega, a member of the Oversight and Accountability Commission (OAC) who participated in the meeting, commented that the AC's work was very important. It emerged from the Surgeon General's report several years ago that found that stigma about mental illness was the single biggest challenge to progress in the entire public health arena, not just mental health. The AC's work was about changing people's views and society's outlook, about the challenges and unjust treatment that consumers and families faced. It was good that people could express their views and that clients have a central voice in the process. Eduardo expressed his pride that the OAC and MHSA supported this work, and that it would be a dynamic and important piece for change.

The next meeting is Wednesday, January 14, 2008, and will be held again at the Sacramento State Alumni Center.

7. Attendance

Committee Members:

Khatera Aslami
Delphine Brody
Rocco Cheng
Rob Chittenden
Serena Clayton
Fran Edelstein
Pia Escudero
Luis Garcia
Marty Giffin
Tish Harris
Susan Henderson
Stacie Hiramoto
Lorna Jones
Janet King
Ruby Lim
Kenneth Logan
Matt Lord
Harriet Markell
Daniel McCarthy
Bonnie Milstein
Sabirah Mustafa
Marie Nitz
Janet Paine
Becky Perelli
Stephanie Ramos
Dede Ranahan

Sharon Rapport
Sean Rashkis
Matthew Reali
Emil Rodolfa
Cuco Rodriguez
Michael Roosevelt
Gregory Sancier
Ron Schrabier
Jenessa Shapiro
Hector Torres
Philip Traynor
Arcadio Viveros
Sue Watson
Stephanie Welch

DMH, OAC, and CCP Staff:

Cielo Avalos, DMH
Kirsten Deichert, DMH
Peggy Fish, California State Library
Dorian Fougères, CCP
Barbara Marquez, DMH
Julia Lee, CCP
Susan Sherry, CCP
Nicole Ugarte, CCP
Eduardo Vega, OAC
Joan Waters, CCP
Beverly Whitcomb, OAC

Appendix A: Strategic Directions – Small Group Work

▷ GROUP 1:
  o Create opportunities with consumers and families respecting diversity of backgrounds
  o Form partnerships and collaborations across multiple systems
  o Advance public policy t end discrimination and enhance legal protections for individuals with mental illness
  o Increase knowledge through evaluation and research to reduce stigma and discrimination in society
  o Implement education and training programs to change attitudes and end discrimination against individuals with mental illness.
▷ GROUP 2:
  o Creating a statewide system for coordinating stigma and discrimination reduction activities /countering stigma and discrimination
  o Creating a culture of inclusion and openness to diversity

- o Providing accountability (and enforcement?) for equal treatment, opportunities and professional standards
- o Collaborate with educators, trainers, and general media
- o Countering stigma and discrimination associated with mental health issues
- o Advancing public policy and legal protections
- o Creating opportunities for consumers and families within their cultural <u>communities</u>
- o Transforming attitudes from deficit model to asset-based, from patienthood to personhood
▷ GROUP 3:
- o Meaningful involvement of the "who" list in design and implementation of all stigma and discrimination programs
- o Improve stigma and discrimination program effectiveness and system accountability (Research)
- o Eliminate barriers to full participation in society
- o Change societal and institutional biases that discriminate and stigmatize
- o Training for systems and institutions that interface with the "who" list
- o Promote awareness and understanding through education and systems collaboration
- o Expand, implement, and enforce the legal rights of persons and communities affected by stigma and discrimination (i.e. the "who" list)
▷ GROUP 4:
- o Reducing internalized stigma in consumer/clients and families/extended families
- o Challenging stigma held by people within institutions and systems that affect people
- o Eliminating and preventing discriminatory practices and holding violators accountable
- o Advancing public policy and legal protections
- o Gaining knowledge on what works to reduce stigma through community- based participatory research, with unserved and underserved communities (including clients/consumers, communities of color, rural)
▷ GROUP 5:
- o Establish a statewide clearinghouse on stigma and discrimination to house and analyze community data, provide T.A., provide resources, oversight of cultural competence across all activities
- o Develop programs to increase understanding and sensitivity of first responders (paramedics, firefighters, police, teachers, secretaries, bus drivers) towards people experiencing difficulties. Heightened understanding of contexts!
- o Strategies that address/effect the entire context (many and varied contexts AND CULTURES) are critical
- o Create programs to support and empower consumers and families to address internalized stigma and learned helplessness
▷ GROUP 6:
- o Creating equality for individuals within their cultural context
- o Partnering with individuals, communities, systems, and networks.
- o Improving individual and family human rights through public policy and legal protections
- o Gaining knowledge through research and evaluation
▷ GROUP 7:

- o Creating opportunities for consumers and families to fully participate in society and in the life of their communities
- o Addressing institutional and organizational policies and practices
- o Advancing public policy and legal protections
- o Gaining <u>and applying</u> knowledge through research and evaluation
- o Increasing public awareness and understanding through education